

Testimony

House Bill 1117

Senate Human Services Committee

Monday, February 14, 2005

North Dakota Department of Health

Good afternoon, Madam Chair and members of the Senate Human Services Committee. My name is Danielle Kenneweg, and I am director of the Division of Cancer Prevention and Control for the North Dakota Department of Health. I am here today to testify in support of House Bill 1117.

In 1992, the United States Congress passed legislation authorizing funding to establish cancer registries in states that did not have them. As a result of that legislation, North Dakota became eligible to apply for cancer registry funding from the U.S. Centers for Disease Control and Prevention (CDC). The North Dakota Department of Health applied for and received that funding in 1994. In order to qualify for funding, applicants were required to provide assurance to the Secretary of Health and Human Services that state law authorizes the statewide cancer registry. This proposed legislation would provide such authorization to maintain the cancer registry as it currently exists.

The North Dakota Cancer Registry is a statewide central registry system that collects incidence and mortality data on all North Dakota residents who are diagnosed and treated for cancer either within or outside the state. Its purpose is to support all aspects of cancer prevention and control (prevention, screening, diagnosis, treatment, rehabilitation and quality of life) by providing quality data and summary statistics. The Cancer Registry supports local public health and health-care providers, agencies and facilities by following cancer incidence and treatment trends, facilitating rapid reporting of cancer and providing accurate cancer data in report formats.

The attached program brochure describes the state Cancer Registry. I would like to take a few moments to describe how the Cancer Registry operates.

When a physician diagnoses cancer, that incident is reported in a patient's medical record. At the larger hospitals in North Dakota, a hospital cancer registry collects information about that cancer incident and enters it into a database in the form of an abstract. On a regular basis, the hospital reports new cancer incidents to the state central registry via an electronic download to a central database. In small hospitals

and independent physician offices, local registries do not exist. In those cases, a staff person in the office or medical records department periodically sends key information from the medical record of a cancer patient to the state Cancer Registry. The state Cancer Registry also receives abstracts, test results and partial medical record information from other facilities, such as outpatient surgical centers, clinics, pathology laboratories, treatment centers; from death certificates; and from central registries in other states.

If partial information is provided, contact is made with the agency or facility to retrieve any missing data elements. If necessary, a staff person travels to the facility to gather the needed information. During 2004, staff traveled to 18 locations in the state for this purpose.

When the data reaches the state Cancer Registry, it is entered into a privacy-protected database. The registry uses a software program to check the validity of data in the numerous fields against a set of acceptable codes. In addition, a staff person who is an expert in quality control reviews data visually.

Each year, state Cancer Registry data is submitted to three major national organizations – the North American Association of Central Cancer Registries, the Centers for Disease Control and Prevention and the Central Brain Tumor Registry of the United States. Each month, the state Cancer Registry processes five to 10 requests for data from citizens of North Dakota, health-care providers, researchers, health-care organizations and others. Federal and state laws protect confidential medical information; therefore, only aggregate data is released and/or published.

Cancer Registry data is used in numerous ways, including:

- Analyzing the burden of cancer in North Dakota.
- Identifying how many residents are diagnosed with cancers.
- Naming the most common types of cancer in North Dakota.
- Recognizing the deadliest cancers in the state.
- Studying trends in cancer treatment.
- Targeting efforts with cancer education, prevention and screening.

This proposed legislation will meet the requirements of the Federal law and allows the North Dakota Department of Health to maintain the operations of the state Cancer Registry. There is no additional fiscal effect and there would be no change in current practice.

This concludes my testimony. I am happy to answer any questions you may have.